

Living Donor Kidney Transplantation

A Failed American Enterprise

2024



Who We Are

The Kidney Transplant Collaborative (“KTC”) is a national not-for profit focusing on kidney transplant with one goal: **to increase the number of kidney transplants in the United States faster.**

We are advancing this goal in two ways:

- **Research**: KTC developed a comprehensive grant program and invited hundreds of organizations to submit funding proposals for innovative ideas around organ transplant. To date KTC has awarded five grants and distributed \$3 million to further these proposals.
- **Advocacy**: KTC is advocating for policies to increase kidney transplants and reduce the financial and unnecessary barriers to transplantation for recipients, donors, and their families. Unlike others in the field, KTC is focused on increasing the number of living donor transplants in the United States.

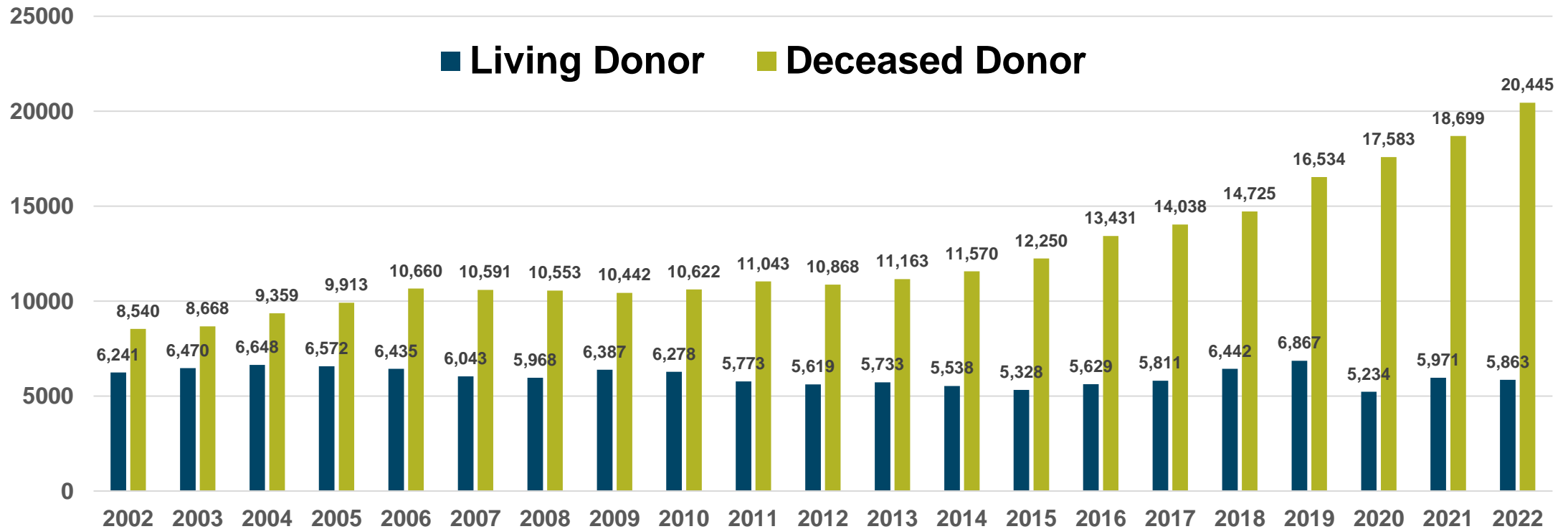
Facts: The US Kidney Transplant Waitlist

- **93,000 Americans** are on the wait list for a kidney transplant.
- **The wait list is growing faster** than the **number of kidneys available** for transplant.
 - We are reaching the limit of available organs from deceased donors; transplants from living donors are needed to reduce the wait list.
- **The average wait for a kidney transplant is 3-5 years.**
- **17 people on the wait list die every day** waiting for a kidney transplant.

Facts about Living Donor Transplants

- A living donor kidney lasts twice as long (est. 20 years) as a kidney from a deceased donor (est. 10 years).
 - Recipients of living donation do not have to go back on the waitlist as frequently.
- A kidney transplant **saves Medicare** at least **\$136,000** per transplant over 10 years.
 - Doubling the living donor rate would save Medicare at least **\$816 million over ten years.**

Living Donor Rates Have Not Moved in 20 Years -- The Current Living Donor Policy Has Failed



Billboards and Social Media Are Not the Solution

He put up a Times Square billboard in search of a kidney - and saved more lives than his own

Marc Weiner booked one of the world's most visible advertising spots, hoping his life would change. He ended up changing the lives of dozens of others, too



There are more than 253.8 million adults in the nation - most of whom presumably have a kidney to spare. Photograph: Marc Weiner

Marc Weiner has two voices. There is his speaking voice, engaging and booming, sharpened over years in front of the

The people using Instagram to find a life-saving kidney donor

Bo Harris says he was not only looking for an organ donation, he wanted to put a face to his largely invisible kidney disease



When Bo Harris needed a kidney, he reached out via social media. Illustration: Guardian Design

Bo Harris was diagnosed with chronic kidney disease in 2015. In the five years since, he has gone to countless doctor appointments, spent weeks in bed with symptoms of the illness such as severe fatigue and body aches, and even battled and beat lung cancer. But the most difficult part of the journey by far, he says, was pushing the publish button on his first Instagram post searching for a life-saving kidney donation.

"It's very out of my nature to have to ask people for anything, and for this, you have to essentially ask, 'Can you donate an organ so I can continue

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How to Use Social Media to Find a Living Donor

February 21, 2020

By Dr. Beje Thomas, Internal Medicine and Nephrology

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Find Care Now

Melissa's Story: Finding a Living Kidney Donor Through Social Media

Apr. 14, 2022

"I do not have the words to express how grateful I am for what she has done for me," Melissa Kinnaird said of her live kidney donor. "It has really changed my life, and it has changed my life for the better."



Melissa posted on Facebook in 2021 seeking a perfect match for a live kidney



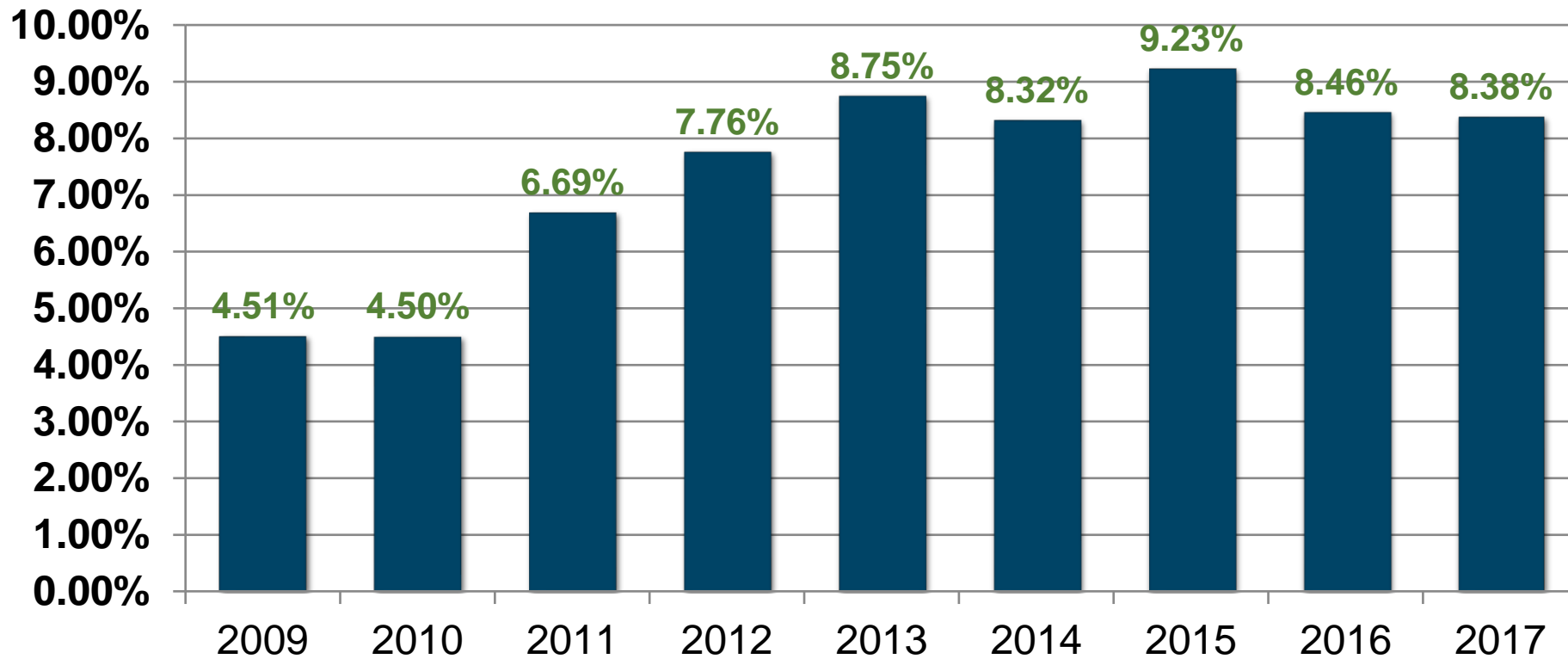
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Reimbursing Donor Costs -- the Limits of the National Living Donor Assistance Center (NLDAC)

2013 – 2017: NLDAC supports approximately 500 of the 6,000 Living Donors per year.



Problem: No National Living Kidney Donor Program

- Living kidney donation is neither nationally organized or donor-centric.
 - Individual transplant programs create and manage their own living donor programs.
 - Transplant coordinators work for the transplant hospital, and not the donor.
 - Non-profits are doing impressive work but are not moving the needle.
- The living kidney donation system lacks meaningful federal structure and support.
 - Proven model – the National Marrow Donor Program (“Be the Match”) -- which has eliminated the wait list for bone marrow transplants and saved tens of thousands of lives.
- A federal program is needed to support and coordinate living donor transplant.
 - Research indicates that less than seven percent of those who even complete a comprehensive living donor questionnaire will make it to the finish line.

What Could A National Program Provide?

- National Education -- so that Americans know they can serve as living donors and understand what is involved
- Donor Navigators -- to assist ESRD patients in identifying potential living donors and help those potential donors through the process
- Appropriate Cost Reimbursement -- to improve NLDAC and ensure living donors do not have to “pay” for the privilege of donating
- A National Living Donor Database -- to maximize available living donations

Solution: The LOVE Act



The LOVE Act – a National Living Donor Program

Education	Coordination	Donor Navigators	Donor Reimbursement
<p>Creates a national public education program to make information available about living donation for:</p> <ul style="list-style-type: none"> ➤ Educating the public about the option of living donation; ➤ Assisting in recruiting eligible living donors; and ➤ Informing potential kidney transplant recipients and professionals about the benefits of living donation. 	<p>Creates the national living kidney donation program to organize federal efforts to increase the number of transplants from related and unrelated living kidney donors.</p> <p>Modeled on the bone marrow program, the living kidney donor program would be run by a federal contractor and would implement similar policies and recruitment efforts.</p>	<p>Builds a networks of donor navigators to connect potential recipients with living donors and guide those donors through the donation process.</p> <p>Establishes best practices to simplify qualifying to be a living donor.</p>	<p>Removes existing National Living Donor Assistance Center (NLDAC) cost reimbursement restrictions based upon the specific income limits of the donor or any income limits of the recipient.</p> <p>Expands cost reimbursement for all direct and indirect costs lost wages of up to \$2,500 per week.</p>

Questions?

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